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ABSTRACT

This paper reports on a portion of a study on community support and respite for families of children with disabilities in New South Wales (Australia). This part of the study focused on identification of factors influencing families when making decisions about caring for their young child at home or seeking an out-of-home placement. The study used ecocultural theory to examine the views of the families themselves. Ecocultural theory proposes that the central adaptive problem of all families is the construction of a sustainable, meaningful, and congruent daily routine of family life. Questionnaires were administered and interviews conducted with 171 families. Respondents were grouped into those definitely not wanting out-of-home care (n=125), those undecided about care (n=32), and those either receiving out-of-home care or seeking such care (n=10). Analysis focused on eight factors: (1) family coherence; (2) proactive involvement and use of special services; (3) integration and quality future; (4) finance; (5) father's involvement; (6) mother's availability; (7) religion; and (8) sibling involvement and concern. Families who did not want alternative care were characterized by a strong sense of responsibility and a desire to provide family care which they viewed as superior to any other type of care. Families who had sought or were seeking alternative care viewed such care as necessary for family survival--physically, emotionally, or socially. (Contains 15 references.) (DB)

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FACTORS AFFECTING OUT-OF-HOME PLACEMENT OF YOUNG CHILDREN WITH DISABILITIES AND HIGH SUPPORT NEEDS

ED 402 716

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During the last decade, government policy and professional opinion on out-of-home placement for children with disabilities has taken an about turn. Previously, families of children with obvious disabilities at birth and ongoing high support needs were actively encouraged to place their children in institutions. The situation today is radically different. There has been, as Baker & Blacher (1993) noted, "a tidal wave of professional sentiment against out-of-home placement" (p. 368). Families are actively encouraged to see their child as an integral part of their family unit and to use services to help care for their child at home.

Despite these changes families still seek alternative care for their children. Regrettably, there are no reliable Australian figures on parental requests for out-of-home placement. However, anecdotal evidence suggests that most professionals have been asked to provide advice about alternative living arrangements especially for those children with high support needs.

What do we know about which families seek alternative care for their children, why they do so and when? One theme is evident from the research literature: those children with the most severe disabilities and the highest support needs are those most at risk of out-of-home placement. This may occur, or be planned at quite an early stage in the child's life (Blacher, 1990; Blacher & Hanneman, 1993; Borthwick-Duffy, Widaman, Little & Eyman, 1992). In the best interests of families and to assist service planning there is an urgent need to identify the factors which influence families in seeking alternative care.

In 1995, the Community Support and Respite Project (Llewellyn, Dunn & Fante, 1995) was funded by the New South Wales Department of Community Services and the Department of Human Services and Health to investigate factors which influence families to seek out-of-home placement for their child. This presentation reports the findings from one part of that project.

Broadly speaking, the aim of this project was to identify the factors influencing families when making decisions about caring for their young child at home or seeking alternative care. To do this, the project design incorporated:
(i) the views of families themselves,
(ii) the perspectives of local community and specialist service providers and personnel from organisations and peak bodies,
(iii) the views of government departmental personnel and the perspectives contained in policy documents and reports, and
(iv) a review of innovative programs and consultations with personnel in several states around Australia.

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This presentation reports the findings from the family part of the project. To investigate the factors influencing families we chose to address the ways in which parents viewed their daily family life. Our approach was based on the belief that, for any family, maintaining a daily routine which balances competing demands such as family member's needs, work schedules, child care, domestic workload and obligations to extended family members, is an ever present challenge. As many parents have reported, when there is child with a disability in the family, the challenge of creating a satisfactory daily routine is considerably greater (Bowman & Virtue, 1993). To understand the influences on families with young children with disabilities and high support needs, we need therefore, to understand how these families view their family life and how they go about meeting the challenge of creating a satisfying daily routine.

Theoretical framework for the project

A suitable model to explore family life and the strategies used by families adapting to childhood developmental disabilities comes from ecocultural theory. This theory has been developed by Gallimore, Weisner and colleagues at the Socio-Behavioral Research Group on Mental Retardation at the University of California, Los Angeles (Gallimore, Weisner, Kaufman, & Bernheimer, 1989).

Ecocultural theory proposes that the central adaptive problem facing families - all families, whether or not they have a child with developmental delay - is the construction of a sustainable, meaningful and congruent daily routine of family life. The question at the core of ecocultural theory is "how do families construct and sustain a daily routine of life that has meaning, and that fits with the competencies and needs of available members of the family and community"?

The central task of organising and sustaining the daily routine occurs through a process named family accommodation (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). Family members work individually and together to create a unique family setting - their ecocultural niche (Gallimore et al., 1989). This does not occur in a social vacuum, rather this setting mitigates and shapes the effects of the surrounding ecological and cultural forces. Accommodation is not just a response to stressful situations, rather it is the central task of everyday family life. In this way, it is explicitly a family level, social unit of analysis in contrast to the individual unit of analysis more frequently encountered in family and disability research (Crnic, Friedrich, & Greenberg, 1983).

Ecocultural theory predicts there will be some similarities in accommodation activity across families according to a posited hierarchy of ecocultural domains developed from cross-cultural anthropological and psychological research (Weisner, 1984). Although there are common ecocultural features across families, families have differing goals, values and beliefs. Families also regard environmental factors differently, either as resources or constraints. A resource regarded positively by one family (e.g., extended family support) may be regarded as a constraint by another. This explains why families in ostensibly similar circumstances construct remarkably different family settings (Gallimore et al., 1989). Most importantly accommodation is not presumed to be of positive or negative benefit to the child, the parent, or the family. Rather it is considered in terms of amount and intensity of family activity in response to a child with a disability (Gallimore et al., 1993).

Ecocultural theory has been applied in research with families with children with developmental delay of unknown origin (Gallimore et al., 1989, 1993). From this research, several instruments for exploring everyday family life have been developed (Ecocultural Scale Project, 1993, 1994, 1995). The ecocultural model and the instruments derived from the Ecocultural Scale Project provide a comprehensive approach to understanding (a) the family context and the resources and constraints in this context; (b) the families' perspectives of their lives and circumstances, including their values and goals; and (c) families proactive efforts to accommodate the child with a disability (Nihira, Weisner, & Bernheimer, 1994). These instruments, suitably adapted for use in the Australian context, provided an appropriate foundation for the current project.

Participating families

The project sought contact with families in metropolitan Sydney, Newcastle, Wollongong and the Riverina with a child aged 0-6 years with a disability and high support needs. Special attention was paid to seeking contact with remote as well as rural families, Aboriginal and Torres Strait Islander families, and families of non-English speaking background. A combination of methods was used to identify and establish direct contact with agencies likely to know potential families including a publicity campaign, a social systems approach (Mercer, 1973), and snowball and personal network sampling. Criteria for inclusion in the study are included in the Appendix.

In total, 171 families participated in the questionnaire and interview phase of the project from May to October, 1995. Just over half (n=95) of the families come from metropolitan Sydney with around one third (n=30) from Newcastle and Wollongong and the remainder (n=59) from the country. The majority (84.2%) of the families are two parent families. Of the mothers among the participating families, around three quarters (75.3%) are Australian born, non-Aboriginal. The average age of the mothers is 35.6 years (sd=6.83) and just over half (60.8%) describe themselves as homemakers.

Around two-thirds (66.5%) of the fathers are Australian born, non-Aboriginal. Fathers' ages range from 22 to 63 years, with the average age being 37.7 years (sd=7.13). Around two-thirds (66.5%) are Australian born, non-Aboriginal. A significant majority (82.8%) of the fathers are in full-time employment.

Of the 171 families, 7 families have more than one child with disabilities and high support needs. Children range in age from 15 months to 9 years, with the average age at 5.4 years (sd =20.03). 110 (64.3%) of the children are male; 61 (35.7%) are female. By far the majority (95.9%) of the children live at home; one lives in a foster home, and six live in residential care. Most (n=99) of the children have multiple disabilities. Over two thirds of the parents (68.8%) think their child will not or may not outgrow their problems or special needs.

Procedures

Families participated by completing a questionnaire and taking part in an interview. We used a modified form of the Ecocultural Scale Short-form Questionnaire (1993 Ecocultural Scale Project, University of California, Los Angeles; 1995 Community Support and Respite Project, University of Sydney). This questionnaire is divided into several sections with forced choice and open-ended questions. The person in the primary mother role completes the Mother's

Information section and the person in the primary father role completes the Father's Information section. These sections include questions about origin, language, education, study commitments, work situation and career beliefs. All other sections comprising information on the family, daily routine, financial resources and child and family services are completed by the person in the primary caretaker role.

The subsequent interview was guided by a modified version of the Ecocultural Scale Family Interview (1994 Ecocultural Scale Project; 1995 Community Support and Respite Project). The family's responses on the questionnaire provide guidance for the interview. The interview seeks to answer four primary questions (Table 1).

The interview format is conversational in style, driven by what is important to the family. It provides the opportunity for the family to "tell their story". Interviews are as open-ended as possible usually beginning with an open-ended question such as "how are things going these days?". Opinions on alternative care were sought at the end of the interview using standardised closed questions with five mutually exclusive alternatives (see Table 2).

Analysis and results

All primary caretaker interviews were coded according to the 54 separate items in the Ecocultural Family Interview Codebook (July 1995, Ecocultural Scale Project) which had been adapted for this project in line with the modifications to the questionnaire and interview. Two coders coded a total of 167 taped interviews (coder 1, n=125; coder 2, n=42). Inter-rater reliability was established by several procedures to 80 per cent agreement.

An exploratory factor analysis of the coded interview data using Principal Components Analysis with Varimax rotation was conducted. This produced a satisfactory definition of eight factors with 44 of the 54 coded interview items having substantial loadings (>.4) on one factor only, with no cross loadings. The eight factors were used to derive scales defined as follows:

Family Coherence,
a positive family affect factor which includes items on meaningfulness and sustainability of daily routine and congruence between needs of child and of other family members.
Proactive,
involvement and use of special services factor which includes items on family activity in relation to information relevant to the child and intervention and activities for the child.
Integration and Quality Future,
includes family goals and view of the current and likely future integration of their child into the everyday world of their family and the community.
Finance,
a financial status not limiting factor which includes items on the overall resilience of, and satisfaction with family subsistence base and affordability of desired services.
Father's Involvement,
which includes items on the availability and participation of the father in childcare and domestic tasks and the help mother receives from the immediate and extended family.
Mother's Availability,
which includes items on availability of mother and the flexibility of her work schedule.
Religion,

family's religious involvement factor which includes items on parent commitment to religion or spirituality and the understanding this brings to having a child with special needs
Sibling Involvement and Concern,
which includes items on the arrangement of the family around the child with special needs and the effect of this on siblings now and in the future.

The scale scores were then used to investigate differences between data from alternative care groupings and disability perception groupings, using one-way ANOVA. Due to the markedly different group sizes on the alternative care question, three groups were formed as illustrated in Table 3. Caretaker perception of disability was collapsed into three groups as shown in Table 4.

In answer to the question **what factors influence families to seek alternative care for their young child with a disability and high support needs?** significant differences were found on three factors as follows.

On the Family Coherence factor there was a highly significant difference (p-value .001) between Group 1 (care definitely not wanted) and Groups 3 (in care and actively seeking care) and 2 (undecided about care). That is, families who answered definitely no to the alternative care question show significantly more satisfaction with their everyday family life in relation to the child with high support needs than do those families who either have chosen or are considering alternative care for their child.

On the Integration factor there was a highly significant difference (p-value <.001) between Group 2 and Group 3 and a highly significant difference (p-value <.001) between Group 1 and Group 3. That is, families in each group differ from each other in relation to the degree which their child is part of their everyday life and integrated into everyday networks in the community. In other words, those families who are definitely not seeking alternative care and those families who are undecided about alternative care view their children much more as part of their family life and integrated into everyday networks in the community than do those families who have already chosen alternative care or who are actively seeking this type of care for their children.

On the Sibling Involvement factor there was a significant difference (p-value <.01) between Group 3 and the other two groups. That is, those families who already have their children in care or are actively seeking care show significantly more concerns about the effect of the child on the family and the involvement of the child's siblings than those families undecided about care or definitely against alternative care.

Overall therefore, the factors which influence families in seeking alternative care are:
(1) lack of congruence in everyday family life with regard to the child with special needs and the needs of other family members (Family Coherence)
(2) lack of integration of the child into everyday family life and the community (Integration and quality future)
(3) concern about the effect of the child on the siblings now and in the future (Sibling Involvement and concern).

The second question we asked was **do families differ on the eight factors according to their child's disability status?** In answer to this question a significant difference was found on the Integration factor only. On this factor there was a highly significant difference (p-value <.001) between multiple disability and intellectual disability and physical/ sensory disability. That is, those families who have a child with a single disability (either intellectual or physical/ sensory) view their children as much more a part of their family life and integrated into everyday networks in the community than do those families whose children have multiple disabilities.

Analysis of the qualitative data from the interviews on the alternative care question was conducted using constant comparative analysis procedures (Glaser & Strauss, 1967). Using these procedures, categories of responses were developed for each of the alternative care groupings as shown in Table 5. The following section briefly reports the main findings from the analysis of the qualitative data.

Care definitely not wanted

The most marked feature of family responses on the "definitely no" option on the alternative care question was the sure and definitive answers given by parents that alternative care was not an option for their family. For some parents, even the very idea of seeking alternative care was rejected. For other parents, the idea had been discussed and rejected.

Values and beliefs about caring for their child

The most common value expressed was that the child was the parent's responsibility and therefore should be cared for by the parent at home and the family manage this situation no matter the extent of the child's disability or the impact of this on family life. Along with this responsibility many of the parents expressed the view that the child's rightful place was with their family as it should be for any child. Many of the families believed that the child received much better care and understanding at home in the family.

Personal feelings about the child

Many primary caretakers expressed their very strong desire to have their child with them, and their reluctance to leave the child even for a short time in the care of someone else. Frequently, parents mentioned that as the child was so young, they naturally expected the child to be in their care and were reluctant to share this care with others outside the family or extended family. For some families, a great deal of attention was given to the worries and fears they held for their child when their child was not with the family. These fears stemmed from parents' concern that other people were not able to understand the child's needs or to care for the child adequately.

Views about who alternative care is for

Many parents emphasised their own views about not wanting alternative care by referring to families or situations that they thought were appropriate for this type of care. Many commented that their child was "not bad enough" for alternative care away from home. Other parents emphasised their "distance" from alternative care. They talked about understanding how other parents could choose this option and the importance of being non-judgemental about this whilst retaining their own firmly held views that alternative care was not an option for their child.

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When asked if any situation could be imagined that would change their decision about definitely not wanting alternative care for their child, around one third of the families could not envisage any situation that would change their view about continuing to care for their child at home. For the remaining two thirds, a change in circumstances was the most commonly given reason for the possibility of having to consider alternative care.

The overwhelming feature however of the families' comments on possible circumstances which would change their views was that alternative care would be "a last resort" and, for some, their "worst nightmare". Frequently, mothers talked quite emotively about severe, drastic events concerning themselves, such as a serious or terminal illness or their death. Some parents envisaged the possibility of their child deteriorating and developing even more complex medical needs and needing hospital care; others imagined the possibility of their child being too large to handle or too difficult to control due to violent outbursts or generally aggressive behaviour. A number of families expected that other members of the family would care for their child before care would be sought outside the home.

Information and knowledge

Many families questioned whether alternative care was available or would be available in the future for their child. For some the possibility had already been mentioned to them. For a few, this had happened when their child was born but, on reflection, rejected by the parents as not right for their family. For many families, the mention of "putting the child away" by professionals or family and friends had been very distressing.

Other parents had been approached more recently about seeking alternative care. For parents with children with high medical needs there was a great deal of concern expressed about the safety of their child among other more mobile, active children, particularly when there was no guarantee that the children would receive care by nurses.

Undecided about alternative care

The most outstanding feature in responses in this group was the "balancing" that families expressed between their wishes to have their child at home and their acknowledgment that this may not always be possible, particularly in the future.

Circumstances

Overall, the most frequent reason given by families for choosing the maybe yes/ maybe no option was a change in one or more aspects of the family situation either in the present or in the future. Most often, families talked about a possible future change in the child, usually a physical change such as the child growing too large or too strong too handle and therefore making care at home no longer possible, particularly care by the mother. Overall, family concerns for the future are perhaps best expressed by the following quote from one mother who said "The idea doesn't appeal, but we just don't know what the future holds!"

Values and beliefs

In all but two instances, families expressed the belief that their child should be cared for at home as part of the family. In the two exceptions, families anticipated that alternative placement may provide a better educational environment for the child and encourage the child to be more independent from the family, respectively. Overall, families regarded the family

situation and the care provided at home to be superior to that offered outside the home.

'Messages' given and received about alternative care
Most families questioned whether alternative care was available or would be available in the future for their child. For some, the possibility had never been mentioned; for others, they had been told to put their name on a waiting list to ensure a place in the future.

In care/ actively seeking alternative care
The overwhelming response by parents who chose this option was that having the child in alternative care was absolutely necessary for the family "to survive". Family survival centred around the wellbeing of the parents, as individuals and in their relationship, the wellbeing of the child including their health and their opportunity to learn and develop, and the wellbeing of siblings including getting their fair share of attention. Parents also talked about how they came to make the decision to seek alternative care for their child.

Wellbeing of parents
In all instances, parents talked about the overwhelming pressures that having a child with such high support needs placed upon themselves and their relationships. One mother summed this up as "we are just trying to keep our family together". Most commonly parents talked about their child's need for 24 hour-a-day attention which was not possible in their family situation. Mothers mentioned sheer physical exhaustion in attempting to meet their child's needs and the needs of their other children. This was a major factor in seeking care irrespective of whether there were informal or formal supports available to the family or whether the father was closely involved in caring for the child or siblings. For some mothers, trying to continually cope with the child's behaviours, which were often repetitive and ongoing such as crying, vomiting, sleeplessness, or aggressive outbursts, was ultimately overwhelming.

Fathers talked about the impossibility of managing work and providing some degree of support to the mother with the child and the other siblings, as well as coping with additional pressures including frequent hospitalisation and economic costs. In several families, fathers had threatened to leave unless the situation changed in the near future.

Wellbeing of the child
Again, in all instances, parents talked at length about their concerns for the child's wellbeing. For those parents who were actively seeking care, there was the immediate concern that their child needed "better" care than they were able to provide. For some, the demands of siblings meant that the needs of the child for stimulation or "therapy" were often overlooked. For others, they were concerned that the pressure of the situation would lead to their "hitting out" at their child, and endangering their safety. For those parents with children with complex health care needs, the needs of the family often cut across the needs of the child. Most parents commented on the need for a steady routine for the child which they simply could not provide because of the needs of other members of the family.

For the majority of the children, there had been major complications at the time of birth with prolonged hospitalisation, and in nearly every instance, advice from medical professionals that the child would not survive. Some of the children, against all odds, had "pulled through" many times. Some continued to have major episodes which were life threatening. In these instances,

parents talked about their relief that the staff were knowledgeable and had the appropriate equipment to care adequately for their child.

Alternative care was seen as being a better situation for the child. For parents whose children were already placed, the stimulation, education, therapy and special outings provided were far superior to what they felt they could provide at home. This was often described as the staff "understanding the child's needs" and being able to provide a stable routine which suited the child. All commented on how the child seemed more sociable and happy in the environment than in the pressured environment of the family home. For those parents seeking care, alternative care was viewed as a better option to the current unsatisfactory situation in which they felt their child's needs were not being adequately met.

Wellbeing of the siblings

Parents expressed great concern about the effects of the child on their siblings. All felt that the siblings had "missed out" on their attention and had missed other opportunities because it was difficult to go out. For most parents, there had been considerable strain on their relationship and great tension in the household which had also affected the other children. For the child's older siblings, there was concern that "they have grown up too quickly" and had to take responsibility beyond that usually expected at their age. Some parents were very concerned about the possible future effects on their other children, particularly the "social stigma" of having a brother or sister with a disability.

'Making the decision'

Despite parents positive support for alternative care, all mentioned that this was the most difficult decision to make - "the decision as to whether or not to keep the child at home or put them in a home is just like ... heartbreaking". All parents wanted to, and did, stay in close contact with their child. For some, children were home for around one third of the week - some weeks; for others, at weekends, if not all weekends. For others though, children did not come home but were visited regularly and sometimes taken out on picnics and outings. Mothers made more frequent visits to their child than fathers; in some families, other family members such as grandparents also visited regularly. For a few families however, there was no contact between extended family and the child once the child had moved out of the family home.

When parents were asked if anything could have made a difference to their decision to seek alternative care for their child, their uniform response was "24 hour care". For the children with medical difficulties, parents wanted 24 hour nursing care; for the other parents, they wanted someone in the home so that they could continue to do all the necessary family activities such as taking the other children to school, going shopping and so on without the child. Having a full time live in nanny, "if you had the money" was frequently mentioned. For some mothers, ideal alternative care would be late afternoon and night time care only, with the child being cared for by themselves during the day while the other children were at preschool or school.

Families whose children were already in care had experienced a range of reactions from other family and friends. Some had been influential and supportive of their decision; others were not

and continued to suggest that the child should be at home. Although some parents had talked with professionals who were supportive of their decision, the overwhelming view was that professionals think parents should cope at home no matter what, and that this is evident in the lack of places for children and the "government shutting places and making it impossible for children to live elsewhere". This has left the provision of places to the private sector which is expensive or requires private health insurance, thereby limiting available options to only those who can pay. Parents felt strongly that this was unreasonable and that alternative places should be available for parents if this is what they wanted and needed.

The following thoughts of one mother speak for many of the parents.

> I think that some people think that you put them in full time care and you've unloaded them and you can forget about them but that's not the case. You don't forget about them, you still know that they're there, you still want to have something to do with them. You are not locking them up and throwing away the key and thinking that he's dead, it's not like that at all. It's just having someone else that can do something better than you can. I don't think that it's fair on the child if you keep the child at home because your next door neighbour says don't put him away. That child is going to suffer because of your selfishness because of 'what are the neighbours going to say'. No, you have to get over that and think that you are doing the best thing for them.

Conclusion

The 171 families who participated in this study were a diverse group of families as are other families in NSW (*NSW Families: A Profile, 1994*). There are however certain characteristics that the families share. Most of the families definitely do not want alternative care for their children. Some families are undecided about care for their child outside their home and some have already sought such care. Not surprisingly, those families who definitely do not want alternative care for their child are more satisfied with their everyday family routine and the way in which their child is included in their family and community networks. Of note, is the influence of child disability on family views to the extent that, in those families with children with multiple disabilities, the children were viewed as being far less involved in family and community life and less likely to be involved in the future.

The qualitative data provide useful support to the findings from the quantitative data. For most of the families a strong sense of responsibility and desire to provide family care - viewed as by far superior to any other - was expressed. Overwhelmingly, a change in circumstances was most frequently given as the reason that would significantly alter family views about alternative care. For the families who had already sought care or were actively doing so, alternative care for their child had become necessary for family 'survival' - physically, emotionally or socially. For these families the decision to place their child had been difficult to make but essential to maintain a satisfactory family life and routine.

In summary, the findings from this part of the project offer insight into the ways in which these 171 families view the question of alternative care and the factors influencing them to seek this care for their child with disabilities and high support needs. Interpretation of these findings

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more widely than this group of families must be viewed cautiously. On demographic characteristics such as place of residence, origin, language and composition of family, the 171 families in this study are broadly similar to other families with young children in NSW (*NSW Families: A Profile, 1994*). However we do not know how many families there are in NSW with young children with disabilities and high support needs nor whether the 171 families who participated in this project are representative of the total population of such families.

As both policy and the families in this project demonstrate, the most favoured option is providing support to the child's birth family to provide care at home. Some families however will need alternative care for their child, and in these instances, permanency planning principles must be applied. These principles give priority to enabling children to live in a family environment throughout childhood and adolescence with an enduring relationship with a parent figure or figures to nurture and advocate on their behalf (Taylor, Lakin, & Hill, 1989). Where the family is unable to do so, then priority is given to finding a placement with another family. This may be an interim arrangement or over the long term. In either instance, the principles of permanency planning dictate that the situation be stable to allow the development of enduring relationships including maintaining the relationship between the child and their birth parents as appropriate.

In conclusion, the family part of this project has demonstrated that for some families alternative care is the preferred option and that the family may seek such care at the very beginning of the child's life. For other families, alternative care may not be their preferred option however for a variety of family reasons, alternative care is sought in the early years of the child's life. For yet other families, alternative care may be imposed due to family crisis or concern that the child is at risk. The need for some families to have access to nurturing, safe and stable alternative care for their children with disabilities and high support needs cannot and should not be ignored.

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Appendix

Critieria for inclusion in the study

1. The child aged 0-6 had a disability which is either physical, intellectual, sensory or multiple.

2. The child receives or is eligible for the Disability Allowance

3. Parents and/or service providers believe the child needs a lot of care and assistance in daily life of an intensity significantly higher than that of children without a disability but this level of high support needs does not necessarily relate to the severity of the disability

4. Local generic child service systems are not able to assist in supporting the family due to the child's high intensity need for support.

To be eligible, families have to fit criterion no. 1, and fit either criterion 2 or 3, and they may fit criterion no. 4.

Table 1. Four primary questions in interview

* What is the *parent's point of view* about their family adaptations? What do they see as their concerns, resources, constraints, goals, values and beliefs?
* What *domains of everyday life* are the parents actively trying to change due to having a delayed child? These might include the child's schooling arrangements, the child's peer contacts, the parents' work schedules. What aspects of daily life are they not changing? Why not?
* What does the parent feel are *the key changes* they would like in their everyday routine? What parts of their daily life do they feel are "not working"?
* What *parts of their daily life do they feel should not be changed*? What do they expect for their child's future? For the family's future?

(Ecocultural Scale Draft Manual, 1994, p. 2)

Table 2. Alternative care options

* Alternative care. That is, my child lives away from home more than 70% of the time in a week.

* Definitely yes. Although my child is living at home right now, I have decided that alternative care would be best, and I am currently seeking such a service.

* Definitely no. That is, I have definitely decided against alternative care for my child.

* Maybe yes/maybe no. Alternative care is a possible option. I have not yet decided one way or the other.

* Lack of choice. I have not been able to consider alternative care because alternative care is not available to my child or I did not know that alternative care was an option.

Table 3. Number of families by alternative care groupings

Group number and description	Number	Percentage
1. Care definitely not wanted	125	74.8%
2. Undecided about alternative care	32	19.2%
3. In care or actively seeking care	10	6.0%
Total	167(i)	100%

(i) Data missing from 6 families

Table 4. Number of children in disability groupings

Disability type	Number	Percentage
Multiple	99	60.7%
Intellectual	27	16.6%
Physical (n=31) / Sensory (n=6)	37	22.7%
Total	163(i)	100%

(i) Data missing from 8 families

Table 5. Categories of responses on alternative care groupings

Care definitely not wanted	**Undecided about alternative care**	**In care/ actively seeking care**
Values and beliefs about caring for their child	Circumstances	Wellbeing of parents
Personal feelings about the child	Values and beliefs	Wellbeing of the child
Views about who alternative care is for	'Messages' given and received about alternative care	Wellbeing of the siblings
Information and knowledge		'Making the decision'